DOI:
10.1007/s00127-012-0475-z

Document Version
Peer reviewed version

Moriarty, A., **Jolley, S**, Callanan, M. Garety, P. (2012). Understanding reduced activity in psychosis: the roles of stigma and views of illness psychosis. Social Psychiatry & Psychiatric Epidemiology, 47, 1685-93.

Understanding reduced activity in psychosis: the roles of stigma and illness appraisals

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Introduction

People with psychosis often suffer reduced quality of life and impaired social functioning [18, 61]. Improving functioning is an important target for health services, both ethically and economically [11, 32,]. In psychosis, difficulties with social functioning have been hypothesised to arise as a result of neurocognitive deficits and negative symptoms [20, 21, 22]. This conceptualisation has favoured interventions based on remedial learning strategies [e.g. 27]. However, the specific skills learnt in remediation therapies do not tend to generalise to functioning in daily life [42]. An alternative therapeutic approach is to target activity levels in order to improve social functioning and quality of life. Increasing activity is a primary focus in cognitive-behavioural interventions, which are both effective and internationally recommended for people with psychosis [13, 42]. Any form of activity which is pleasurable or achievement-focused is encouraged. Compared to the ability/competence component of social functioning, variability in activity levels is more closely associated with changes in positive symptoms and affect [25, 26, 40, 44, 46, 60]. The relationship between activity, mood and positive symptoms suggests a number of therapeutic strategies that might increase activity and hence improve quality of life in psychosis – for example, addressing anxiety or depression, or reducing safety behaviours associated with distressing beliefs or voices. Cognitive behavioural interventions have been shown to improve social functioning outcomes and activity [42]. However, results are mixed and effect sizes are, at best, small to medium. In order to develop the most effective interventions, a better understanding of the psychological processes mediating reduced activity in psychosis is required.

Jolley, Garety, Ellett et al. [29] investigated a number of theoretically derived candidate cognitive, emotional and social mediators of activity levels in psychosis, including affect and intellectual functioning. They found that only negative symptoms and positive symptom

distress were significant cross-sectional correlates of activity. The majority of the variance in activity levels remained unexplained. The findings suggest that the key psychological processes influencing activity in psychosis are yet to be identified, and that there are significant gaps in our current understanding.

An important area which was not examined in the Jolley et al. study [29] was the person's beliefs about their difficulties. Subjective perceptions of physical illness influence the person's experience of their illness, their emotional adjustment and their subsequent recovery. Beliefs about the seriousness of the impact of the illness, about the person's own ability to bring about change, and about the relevance, effectiveness and possible deleterious effects of treatment are key [4, 45]. In schizophrenia, negative beliefs about illness are associated with reduced quality of life and a range of negative emotional reactions, such as depression, anxiety, shame, social anxiety, and reduced self esteem [e.g. 2, 3, 35, 56, 59]. There are several routes, therefore, by which illness appraisals could influence activity. To date, this relationship has not been investigated.

Illness perceptions are not synonymous with the recognition of illness, or insight – indeed, the two concepts are not closely associated [59]. Illness perceptions are measured by asking what the person thinks about their current problems or difficulties. Recognition of 'illness' in the medical sense is not necessary: it is possible to report significant life impact of problems without recognising them as having any internal or medical cause. The relationship of insight to outcomes and improvement in quality of life is complex, and may be mediated by the meaning of the illness label. Generally, positive associations are found for components relating to acceptance of treatment but not for acknowledgement of illness alone. [6, 24, 38, 43, 55]. Given the association between insight and quality of life, a similar relationship of insight with activity levels could be hypothesised.

A third component of illness appraisals concerns public perceptions of the illness and an individual's reaction to this. Stigmatization of people with mental illness is recognised as a significant global public health problem and stigma reduction to be an international health priority [e.g. 33, 57, 14, 17, 34, 63] Dickerson, Sommerville, Origoni et al. [12] describe stigma in psychosis as an experience of being devalued and discriminated against by others. The discrimination experienced can be extreme and damaging [50]. People respond differently to experiences of stigma, and fear of stigmatisation is not necessarily related to experienced discrimination [e.g. 7, 39, 58]. Internalisation and negative reactions are most common, but people may also feel unconcerned or unaffected, or even empowered [51, 52, 53]. Internalizing stigma is associated with a range of negative affective, clinical and social outcomes including depression, low self-esteem; reduced quality of life; reduced treatment adherence; poorer social functioning and less social inclusion [17, 25, 36, 37, 38]. Stigma resistance, in contrast, is associated with positive affective and social outcomes, suggesting that changing self-stigmatising beliefs can act as an aide to recovery [5, 16, 53]. However, to date, only a small number of interventions have been reported, and their impact on activity levels has not been considered [16, 31, 41, 49]. Lysaker et al. [36, 37] report medium to large effects of perceived stigma on interpersonal functioning and social withdrawal, providing strong justification for hypothesising a relationship between perceived stigma and activity levels.

The aim of this study was to clarify the relationship of perceived stigma, illness perceptions and insight to variation in activity levels. Specifically, we wished to investigate whether these factors explained more of the variation in activity levels than the previously identified correlates: cognitive deficits, anxiety and depression, symptom severity and distress. Demonstrating a relationship between illness appraisals and activity would suggest a new

therapeutic route to improve interventions designed to increase activity and improve quality of life and functioning for people with psychosis. Hypotheses were:

1. Increased perceived stigma will be associated with reduced activity levels.
2. More negative perceptions of illness will be associated with reduced activity levels.
3. Less insight into the need for treatment will be associated with reduced activity levels.
4. Illness appraisals (as listed in hypotheses 1-3) will explain more of the variance in activity levels than the known correlates: depression, anxiety, psychotic symptoms and cognitive deficits.

Method

Participants

Fifty participants were recruited from three community adult mental health services within a single NHS trust and gave written, informed consent to take part in the study (Ethical approval was granted by the South East London Research Ethics Committee; ref 08/H0805/10). Inclusion criteria were: aged 16 – 65; primary diagnosis of schizophrenia spectrum psychosis, from case notes [62]; and speaking sufficient English to complete the assessment battery. Participants were all settled in the community; people experiencing a current acute relapse of psychotic symptoms were not targeted for recruitment.

Measures

Demographic and clinical data were obtained by self-report and confirmed with the medical record and clinical team: age, sex, ethnicity, marital status, living circumstances, family contact, illness length and medication. All measures were completed at the participant's pace over a single, individual meeting of 50 - 90 minutes, at a mental health team base local to the

participant. The first author administered all the measures, and was trained to competence in their delivery.

Time Budget [28]. This is a week-long diary of activity which is completed during a semi-structured interview. Each day is divided into four time periods and each period is scored according to the level of effort and motivation involved in the activities undertaken. The interviewer specifically enquires about the degree of planning, participation and social contact involved in reported activities in order to ascribe a rating, from 0 to 4. A zero rating would be given for an activity such as 'sleeping'; 'just lying on my bed'. An activity such as watching television would score 1; a more active but brief activity, such as taking a short walk, or telephoning a family member would score 2; a number of these activities, or longer duration, more complex or demanding activities (e.g. 'I went to church on the bus for the morning' or 'I played chess with my friend') would score 3 and a series of complex and demanding tasks would score 4 (e.g. mainstream employment or education; complex leisure or domestic activities: 'arranged to meet a group of friends at the shopping centre, did my Christmas shopping, went to a restaurant with another friend, played pool with my brother'; 'got the kids ready for school, gave them breakfast, dropped them off, cleaned the house, did the laundry'). The measure prioritises observable, rather than mental, activity, but does not make distinctions between leisure and 'work' – complex and demanding recreational or voluntary activity can be scored highly. Scores from all time periods are added together to obtain a total score of activities for the week. The frequency of each score (0-4) is indicative of the range of activity undertaken over the week. . The measure shows good inter-rater reliability (Intraclass correlation: $r = 0.99$, $p = 0.001$) and test-retest reliability ($r = 0.83$, $p < 0.001$) amongst people with psychosis [27, 28].

Brief Illness Perception Questionnaire (BIPQ) [4]. Participants' perceptions of the duration, impact and amenability to management or cure of their illness are self-rated over 8 items on a

scale of 0 to 10. Higher scores indicate more positive and adaptive views of illness. The ninth item allows participants to rank the three most important factors they believe caused their illness. The BIPQ has been found to have good test-retest reliability (r = .42 - .73) and good concurrent, predictive and discriminant validity [4].

Internalised Stigma of Mental Illness Scale (ISMI) [48]. This 29-point self-report scale rates current feelings and beliefs about experiences of stigma from 1 (strongly disagree) to 4 (strongly agree). A total score and five factors are generated: alienation, discrimination, stereotype endorsement, social withdrawal and stigma resistance. High scores indicate greater internalised stigma. The scale is reliable and has good validity, with high internal consistency (alpha =0.90) and good test–retest reliability ($r = 0.92$, $p < 0.05$).

Hospital Anxiety and Depression Scale (HADS) [65]. This is a 14-item scale measuring the presence and severity of symptoms of anxiety and depression during the last week on a scale of 0 – 3. Good internal consistency and concurrent validity with psychiatric interview ratings are reported for each subscale [65].

Positive and Negative Syndrome Scale (PANSS) [30]. Symptoms are rated on a scale of 1 (*absent*) to 7 (*extreme*). The scale is widely used, with good psychometric properties. In the current study, only positive and negative symptom scales were used. Internal consistency was acceptable (Cronbachs alpha = 0.58 for PANSS Positive and 0.7 for PANSS Negative). The distress items from the Psychotic Symptoms Rating Scale (PSYRATS) [23] were also completed. A single positive symptom distress score was calculated by summing the intensity of distress items from the hallucination and delusion scales [as in 29].

The Schedule for the Assessment of Insight (SAI) [10]. This is a 7-point scale rating of participants' agreement with treatment and diagnosis and their subjective explanation of their

psychotic illness. Items are rated on a scale of 0 (*no insight*) to 2 (*good insight*) with a maximum total score of 14. The scale has been widely used with people with psychosis, and shows good comparability to concurrent ratings of insight [10].

Cognitive functioning: Mini Mental State Examination (MMSE) [15]; Trail Making Tests A& B [47]. The MMSE assesses current cognition (attention, orientation, memory) on a 30 point scale. It has shown very strong associations with social functioning [20]. The Trail Making Tests A & B [47] are widely used as a measure of executive functioning.

Design and analysis

A cross-sectional correlational and regression analysis was planned. The study was adequately powered to detect a large effect size (r^2=0.4) [9], as found by Lysaker et al. [37]. Power analysis for a multiple regression analysis with ten predictors indicated that 38 participants would provide 80% power to detect an effect size of this order, with alpha set at 0.05. All analyses were conducted using SPSS 16.0 for Windows [54]. The data were normally distributed and therefore parametric statistics were employed. The relationship between activity and demographic variables was examined using correlational analyses and one-way ANOVA for categorical variables. Pearson correlations were used to assess the relationships between activity and the hypothesised contributory variables. A linear multiple regression analysis was used to determine cross-sectional predictors of variance in activity.

Results

Participants

Demographic variables are shown in Table 1. All participants except one were taking antipsychotic medication. No participant was in paid employment. Participants reported similar activity levels (Table 2) to a comparable population [29]. No correlation between activity and age was found ($r = -0.15$, $p = 0.30$), and no differences in activity were found in relation to diagnosis, antipsychotic medication type, social circumstances, marital status, ethnicity, gender, length of illness or number of hospital admissions (F values all < 1.0, p values all > 0.1). A relationship was found between activity and living circumstances ($F = 5.70$, $p = 0.01$) and activity and family contact ($F = 6.35$, $p = 0.02$). Participants living alone reported lower activity levels than those living in supported accommodation or with more frequent family contact. However, only a small proportion of the sample had frequent family contact (N = 10) or lived independently (N = 6).

Hypothesis one: Is internalized stigma associated with activity?

Significant correlations were found between total internalized stigma and activity ($r = - 0.33$, $p = 0.02$), such that higher stigma was associated with reduced activity. In the subscale scores, the strongest association was between perceived discrimination and activity ($r = -.43$, $p < 0.01$). The correlations with the remaining four other subscales failed to reach significance (all r values < 0.3; p values all ≥ 0.05).

Hypothesis two: Are more negative perceptions of illness associated with activity?

No significant correlation was found between illness perception total score and activity ($r = 0.05$, $p = 0.74$).

Hypothesis three: Is insight associated with activity?

There was no correlation between any component of insight and activity (all r values < 0.15, p values all > 0.30).

Hypothesis four: Do illness appraisals explain additional variance in activity levels?

No correlations were found between activity and anxiety, depression, positive symptoms, general cognitive function or executive function (all r values ≤ 0.2, p values >0.1). A positive correlation of medium effect size was found between increased positive symptom distress and increased activity (r = 0.34, p = 0.02). A negative correlation of medium effect size was found between severity of negative symptoms of psychosis and reduced activity (r = -0.38, p = 0.01).

A series of linear regressions with activity as the dependent variable was carried out (see Table 3). For the first regression model, only those variables significantly correlated with activity were entered (living circumstances, family contact, ISMI total stigma, ISMI perceived discrimination subscale, PANSS negative symptom total, PSYRATS distress index). The model was significant (r = 0.69, $F(6,43) = 6.59$, $p < 0.001$) and accounted for 40% of the variance in activity levels (adjusted $r^2 = 0.40$). Each variable made a successive contribution to the amount of variance in activity accounted for, with the exception of contact with family ($\beta = -0.03$, $p = 0.84$). Excluding family contact slightly improved the model fit and the percentage of variance in activity accounted for (r = 0.69, $F(5,44) = 8.08$, $p < 0.001$; adjusted $r^2 = 0.42$). Collinearity statistics indicated that both tolerance (>0.8) and variance

inflation (<1.2) were within acceptable limits, with the exception of the total stigma and perceived discrimination variables, which as expected, shared common variance, but still each made a separate contribution to the variance in activity.

The variables initially hypothesized to be associated with activity were then added into the model one at a time, to allow the contribution of each to be assessed. These variables were: PANSS positive, HADS, MMSE and Trail Making Tests. None of the variables added increased the percentage of the variance accounted for, or showed a significant association with activity (β values all ≤ 0.21; p values > 0.05; $r = 0.73$, $F(11,37) = 3.87$, $p < 0.001$). Overall the proportion of variance explained was very slightly reduced (adjusted $r^2 = 0.39$).

Discussion

Summary

Internalised stigma, and particularly the perceived discrimination component, was found to be a significant predictor of activity levels in people with psychosis. In the regression analysis, the inclusion of internalised stigma as a predictor increased the amount of variance in activity levels accounted for to 42% - a substantial improvement on previous studies. Both the total score and the perceived discrimination factor were significant predictors, but the relationship with perceived discrimination was particularly robust. Contrary to hypothesis, neither illness perceptions nor insight were associated with activity. The findings suggest that it is fear of what others will think of them and how they will be treated that limits the activities of people with psychosis, rather than specific illness appraisals. This is consistent with recent developments in narrative therapies, where the meaning of the illness or illness

label in the full context of the person's self concept and life story is argued to be a critical determinant of recovery (49, 64].

Consistent with the findings of Jolley et al. [29], negative symptoms and positive symptom distress were significant predictors of activity. However, contrary to expectation, distress was associated with increased rather than reduced activity. This finding could be explained by participants employing avoidance as a strategy to manage positive symptom distress, such that low activity results in less distress. Conversely, the mild stress of increasing activity could result in increased distress. Another explanation may be a level of care effect due to people with distressing psychotic experiences being offered increased organized activities. This is likely given that the majority of participants were living in supported accommodation in which regular group activities were established. The relationship between positive symptom distress and activity requires more careful investigation in a larger sample.

Also in contrast to previous studies is the absence of a relationship between activity and either general cognitive functioning or executive functioning. It is possible that this reflects the different processes involved in reduced social functioning, a construct which includes notions of competence and ability, compared to reduced activity, which can be limited despite high levels of competence and ability, or, conversely, be high despite low levels of competence or ability. Cognitive functioning is a substantial and reliable predictor of social functioning, but the evidence for its association with activity is limited and equivocal [20, 21, 40].

An unpredicted relationship was found between activity and two social support variables: family contact and supported living. It is very plausible that more social support increases activity. However, as there was very little variability in the current sample in relation to these variables, further investigation with participants in a wider range of living situations will be required.

Limitations

The first limitation is that the study is cross sectional and therefore inferences about cause cannot be drawn. The conclusion that internalised stigma leads to reduced activity is theoretically appealing, but equally, perceptions of stigma could be increased by limited engagement in activity. A longitudinal study is required to clarify the direction of the relationship. Secondly, the sample was selected on the basis of convenience, rather than a systematic recruitment programme. Consequently, it is possible that the participants are not representative of people with psychosis and that the sample is biased or distorted. However, this method of recruitment is not unusual for small stand-alone studies which are not associated with a large clinical trial. Further, comparison to the literature suggests that the activity and symptom levels of our participants are similar to those found in larger studies, which have employed systematic recruitment strategies. Thus, our participants appear to be sufficiently representative of a group of people with psychosis receiving care from community mental health teams. The sample size was determined according to previously reported effect sizes, but was small for a regression analysis with multiple predictors. Nevertheless, as the results are fully replicated in the correlational analyses, we do not consider this to impact on the conclusions which can be drawn from our findings. Although

all participants had a diagnosis of functional psychosis of the schizophrenia spectrum, we did not assess for history of brain injury and this may be a confounding factor. Finally, the study measured only perceived discrimination rather than experienced discrimination. It is possible that perceptions of discrimination arise from actual discriminative experiences and therefore the contribution of experienced discrimination to reduced activity will be important to assess in future studies.

Implications for future research and clinical practice

The strong relationship between activity and internalised stigma, and particularly perceived discrimination, indicates new therapeutic strategies that could be helpful in increasing activity and consequently improving functioning and quality of life for people with psychosis. Our findings suggest that specifically targeting an individual's worries about how they will be treated and received by others will help to improve activity levels. These fears should be amenable to cognitive behavioural interventions. There are comparisons to be drawn with the work of Grant & Beck [19], who have identified defeatist beliefs as a mediating factor in the relationship between negative symptoms and impaired functioning, and have evaluated cognitive therapy strategies to improve functioning through this route. Specific cognitive and behavioural interventions could form a useful adjunct to recovery-focused narrative therapies which address the broader impact of illness on the person [49, 64]. Increasing individual resilience to stigma and promoting adaptation and recovery should complement public information campaigns and interventions to reduce discriminatory attitudes and behaviours [e.g. 14].

It is of note, that although this study improved upon previous studies in accounting for variability in activity levels, over half of the variance in activity within the sample was not accounted for. Jolley et al. [29] suggest employment opportunities and medication compliance and side effects as possible contributing variables requiring investigation. These factors should also be investigated in a larger, longitudinal study.

A final consideration is the possibility that the perceived discrimination subscale taps actual experience of discrimination, rather than fears of potential discrimination. Discrimination is a common experience for people with psychosis. Adverse social experience is a known vulnerability, triggering and maintaining factor for psychosis, and victimisation experiences constitute a particular risk for the development of psychosis. Extreme discrimination could contribute to reduced activity through a traumatic avoidance route, or by limiting opportunity through social exclusion, and further examination of experienced discrimination in relation to activity levels would illuminate this relationship [1, 7, 8, 50].

Conclusion

People with psychosis are less active if they report higher levels of internalized stigma. Individuals' fears about how others will react to them could drive social and behavioural avoidance and limit their engagement in meaningful activity. Targeting these fears using cognitive behavioural strategies is likely to improve functioning and consequently quality of life for people with psychosis, and could both form a useful adjunct to recovery-focused therapies and complement campaigns to reduce societal stigma. Longitudinal studies, and further investigation of the contribution of the potentially traumatic impact of lived experience of discrimination are required in future research.

Acknowledgements

This work was supported by the Department of Applied Psychology, Canterbury Christ Church University, Salomons Campus, in partial fulfilment of the award of doctorate in clinical psychology.

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